

Early life trajectories for adolescents with Autism Spectrum Disorder, a Millennium Cohort Study.

Thomas Bombarde, Durham University

Supervised by Prof. Amanda Sacker and Dr Noriko Cable,
Department of Epidemiology and Public Health at UCL

6th of September 2021

The Laidlaw Research and Leadership Programme

Word Count: 5269 (excluding references and footnotes), 6517 total



Abstract

Introduction and aims - ASD is a developmental condition that has been identified in 581 cohort members of the Millennium Cohort Study (MCS), a representative-population based cohort in the United Kingdom. This study sought to determine whether 280 of these cohort members with ASD were (1) more likely to be in neither education, employment, nor training (NEET) at age 17, (2) whether socioeconomic variables or the timing of their diagnosis predicted NEET status and (3) whether ASD diagnosis predicted cohort members' answers to questions concerning their projected achievements for 30 years old.

Methodology - This study opted for a complete case analysis, computing Fisher's exact test for significance, and constructing a binary logistic regression models for each outcome.

Results - (1) Cohort members were found to have 3.01 times higher odds of being in NEET (p-value<0.01, 95% confidence interval: [2.01; 4.75]), with 9% of those diagnosed in NEET. (2) NEET status for cohort members with ASD was predicted by late diagnosis (odds ratio for those diagnosed after 11: 5.44, p<0.01, 95% CI: [3.04;9.74]), low household income (OR for those in the two lowest UK income quintiles: 3.76, p<0.01, 95% CI: [2.92;4.84]), having carers with poor mental health (OR: 2.78; p<0.01; 95% CI: [1.91;4.04]) or not in work (OR: 3.12; p<0.01; 95% CI: [2.31 ; 4.21]), and high behavioural difficulties (OR: 4.00, p<0.01, 95% CI: [3.05;5.32]), whereas cognitive delay failed to show significance. (3) Finally, cohort members were 5.12 times more likely to hold none of the life achievements listed by the interviewer (p<0.01, 95% CI: [2.03;12.93]). Those diagnosed late had higher social but lower professional projected achievements than those diagnosed earlier.

Conclusion - These results corroborate the effectiveness of early diagnosis and intervention in improving the prospects of ASD children. As such, they could suggest that adolescents with ASD in NEET may owe their status more to a lack of intervention (late diagnosis and high social difficulties) rather than cognitive ability. Thus, early life trajectories for those living with ASD could benefit from greater investment in more widespread and later interventions and training.

Background

Autism spectrum disorder (ASD) is a complex developmental condition that involves persistent challenges in social interaction, speech and nonverbal communication, and restricted/repetitive behaviours (American Psychiatric Association, 2013). There can be some confusion over links between ASD and intellectual disability, however dual-diagnosis can in fact vary widely¹ (Knapp, M. *et al*, 2017, p9-10).

Considerable progress has been made over the last 50 years on both the definition of ASD and the prospects of people that live with it (Lord, C. *et al*, 2017, p508). Nevertheless, ASD remains a financial drain. As of 2014, the total cost of autism (taking healthcare expenses and opportunity cost into account) was estimated at “£3.4 billion (US \$5 billion) per year in the United Kingdom” (Buescher AVS *et al*, 2014, p.724), exceeding “heart disease, cancer and stroke combined” (Knapp M. *et al*, 2017, p14). While research in 2017 was only £4 billion, Knapp *et al* advocate that “it is possible to improve the quality of life of autistic people and their families while at the same time reducing this huge economic cost” (2017, p44).

Consequently, research requires further investigation into the factors that influence lifetime trajectories of individuals with ASD (Howlin P, Migiatl I, 2017, p69). So far, and despite high variability due to the difficulty of longitudinal analysis, studies in the USA have found ASD adults expect “limited social integration, poor job prospects and high rates of mental health problems” (Howlin P, Migiatl I, 2017). Meanwhile, Australian studies have echoed the positive impact of early intervention (Clark, M *et al*, 2017). In the UK, the Millennium Cohort study has been used to measure the prevalence of ASD (Russel, G. *et al*, 2014) as well as investigate the determinants (Hosozawa, M. *et al.*, 2020) and the importance of an early ASD diagnosis (Hosozawa, M. *et al.*, 2021). Greater light has been shed onto how parental involvement and poverty influence the development of psychopathology for individuals with ASD (Midouhas, E. *et al.*, 2013). Moreover, findings have shown ASD cohort members display lower quality decision making at age 14 (Hosozawa, M. *et al.* 2021). As advised by Howlin (2017), such insights should be complemented by studies of broader life trajectories.

This project takes investigates the transition into adulthood of adolescents’ with ASD within the MCS. Three hypotheses are tested for cohort members at age 17. First, that adolescents with ASD are more likely to be in NEET. Second, that certain socio-economic factors predict NEET for individuals with ASD. Third, that ASD diagnosis predict answers to questions about the cohort member’s perceived achievements by age 30. As such, this report hopes to enlighten how people with ASD begin adult life. Such updates could aid policymakers, schools, societies, and families living with ASD.

Methodology

Study population

This project draws from the [Millennium Cohort study](#), a longitudinal survey of 19,243 families with children born in the United Kingdom between September 2000 and January 2002 (Hansen K, 2014). The survey only collects information on ASD diagnosis until the 6th sweep at age 14, at which point the total number of diagnosed cohort members was 581 (Hosozawa, M. *et al.*, 2020). Opting for a complete case analysis, the population was reduced to 280 ASD diagnosed cohort members out of a total of 7,916.

Potential predictors were drawn from the MCS6 (age 14) or MCS3 (age 5). Outcome variables were extracted from MCS7 (age 17). All data was obtained from the UK Data Archive. MCS is approved by the UK National Health Service Research Ethics Committee. The use of anonymized data for academic purposes and the written consent obtained from all participating parents at each survey. did not require additional ethical approval.

¹ from 13% to 80% of ASD individuals with a cognitive impairment (Knapp, M. *et al*, 2017, p9-10)

Outcomes

Being in Neither Education, Employment nor Training (NEET)

MCS 7 sweep invited cohort members (CM) to self-complete 2 questionnaires. In the cohort member computer assisted personal interview (CAPI), the young person was asked whether they were in any form of employment, education, or training. When answers were missing, answers to their child's status in the carer's interviews were used instead. If the CM or their carer failed to report any of the three activity statuses, the cohort member was labelled as NEET.

Projected life achievements at 30

In the "Learning and the Future" section of the MCS7 Young Person web questionnaire (CAWI) (Fitzsimons, E. *et al*, 2020, p57), CMs were asked, "By the time you are thirty, which of the following do you think you will have achieved: being in a worthwhile job?(1) - having a partner?(2) - having children?(3) - owning your own home(4) - having a car(5) - having a good car(6) - earning a lot of money(7) - being famous or making a name for yourself(8) - having a personal achievement in sport, the arts or travel etc. - none of the previous achievements? (9)". This study utilised answers to questions 1, 2, 3 and 9. A binary variable grouped all negative answers ("Not applicable", "Refusal", "Don't Know" or "No") against those that answered "Yes".

Predicting variables

Autism Spectrum Disorder (ASD) and timing of diagnosis

Hosozawa *et al* (2020)'s study previously constructed a dataset with ASD diagnosis timing for all cohort members in MCS6. Cohort members were registered as having "never received diagnosis", received diagnosis "by age 5" (MCS3), "between ages 5 and 7" or "between 7 and 11" based on parents' answers to survey sweeps 3 to 6. For this project, a further variable was generated contrasting cohort members without an ASD diagnosis to those diagnosed by age 11.

Household income

In MCS6 as in other sweeps, participating carers were asked the "total amount of income from all sources and earnings after tax and other deductions" (Fitzsimons, E. *et al*, 2020, p70). After imputation for missing values, the average of each carer's answers was weighted and classed into the UK's lowest to highest income quintiles using the OECD approach. This study grouped household income groups based on belonging to the two lowest UK income quintiles.

Difficulties on the Strength and Difficulties Questionnaire (SDQ)

The MCS6's SDQ is a behavioural questionnaire for 4- to 17-year-olds CMs reported by a parent (Fitzsimons, E. *et al*, 2020, p75). A total difficulties score is obtained by summing four scales of 5 on emotional symptoms, conduct problems, hyperactivity/ inattention, and peer relationship problems. All five of these scales were dichotomized using cut-off points in a previous MCS study, at 5% of the highest scores after weighting (Kelly, Y. *et al*, 2012). The total SDQ score with all five categories was kept for a more descriptive binary logistic regression model of NEET for ASD diagnosed CMs.

Carer variables: work and mental health

This study derived two variables from the MCS6 parent's questionnaire. The first - poor parental mental health - was constructed by taking the carer with the highest Kessler 6 score for each cohort member and applying a cut-off point at ≤ 13 (Kessler RC., 2003). Taking both carers' answers to employment in any kind of professional

activity yielded the second derived variable, which identified whether there was at least one cohort member's carer in work.

Covariates

Alongside predictors, several covariates were tested for significance. These included: parental partnership status, identifying as Black, Asian, or other Minority Ethnic group (BAME), whether the CM's household spoke English household, number of siblings, the UK interview region (as groups of counties) of the MCS interview, the sex of the cohort member, low prosocial scores on the SDQ and cognitive delay.

Binary variables were constructed to evaluate having >1 sibling, low prosocial scores, and cognitive delay. Firstly, cohort members with more than one sibling were grouped as having multiple siblings. Secondly, the cut-off point for the SDQ prosocial scale was chosen by weighting the MCS survey data and taking the lowest 5% of scores. Cognitive ability was constructed from three [British Ability Scale](#) belonging to [MCS3](#) (age 5). The cognitive delay variable was created by taking the mean of the cohort member's three BAS II subscales evaluated at age 5 and dichotomising at the cohort average minus one standard deviation.

Statistical Analysis

Due to a relatively small sample size, all variables were dichotomised, except time of diagnosis, and tested for a relationship with outcome variables using Fisher's exact test (Sprent P., 2011).

The analysis tested this project's three hypotheses. For the first, Fisher's exact test was applied to ASD diagnosis and NEET before constructing a binary logistic model for NEET with ASD diagnosis as a single independent variable.

As for the second hypothesis – certain socioeconomic factors predict ASD cohort members' of being NEET - significance tests for each covariate were applied exclusively to the ASD diagnosed cohort. Subsequently, the same tests were applied and compared to predictors of NEET for cohort members without ASD. A binary logistic regression model for NEET was computed for each covariate coupled with ASD. Predicted probabilities of NEET were calculated for SDQ scores and carer's mental health from MCS6. A concluding logistic regression model was generated with ASD diagnosis and all other predictors.

The third hypothesis, that ASD diagnosis predicts answers to projected life achievements for age 30, was tested identically to the first. Each dichotomised answer was tested for significance with ASD using Fisher's exact test before the construction of a binary logistic regression model.

All manipulations were computed using Stata 16 (StataCorp, 2019) & 17 (StataCorp, 2021).

Results

Hypothesis 1: ASD diagnosis predicts NEET status

The substantial impact of ASD diagnosis and its timing on the odds of being in NEET at age 17 are presented in Table 1.

Table 1: Odds Ratio of being in NEET as predicted by ASD diagnosis and its timing

	OR	Std. error	p-value	95% CI lower	95% CI upper
By ASD diagnosis:	3.088*	.679	<0.0005	2.007	4.750
<i>with diagnosis</i>					
By timing of diagnosis:	.617	.625	<0.6339	.085	4.487
<i>by age 5</i>					

<i>between 5 & 7</i>	4.845*	2.622	<0.0045	1.677	13.994
<i>between 7&11</i>	1.948	.829	<0.1175	.845	4.488
<i>after 11</i>	5.443*	1.616	<0.0005	3.042	9.741

Of the 280 ASD individuals, 25 - approximately 9% - were reported in NEET. For those without an ASD diagnosis, 255 were NEET out of 7,636, so around 3%. The statistical analysis confirmed the odds of being NEET to increase by a factor >300% (95% CI: [2.006;4.750]) for ASD individuals, with strong significance (p-value<0.000). As visualised by figure 1, risks increased with timing of diagnosis; late diagnosis resulted in even greater odds, 194.8% times higher for those diagnosed between 7 and 11 years old (95% CI : [0.845;4.488) without significance and 544% higher for those diagnosed after 11 (95% CI: [3.041;9.741], p-value<0.000). Figure 2 showcases the over-representation of later diagnosed cohort members in NEET status. More than 50 % of those in NEET with ASD are diagnosed after 11, whereas this group makes up less than 40% of the ASD cohort not in NEET.

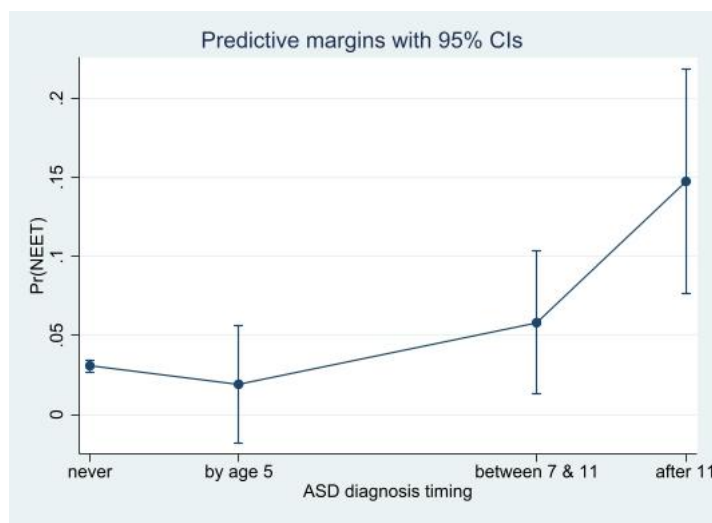


Figure 1: Predictive margins for being in NEET with CIs by timing of diagnosis

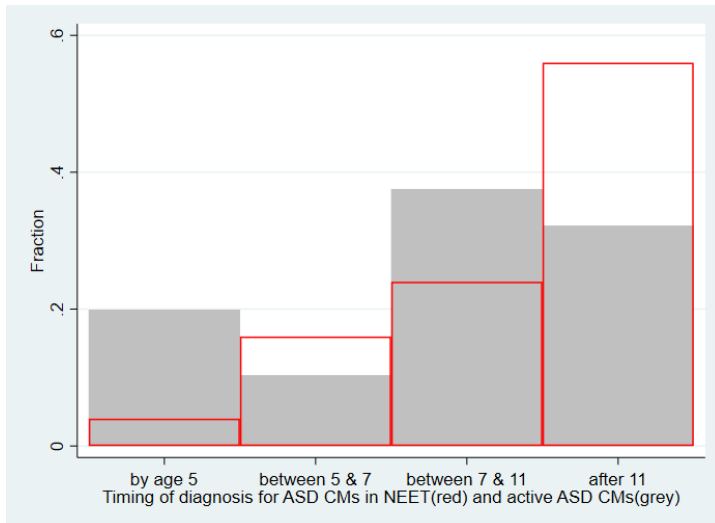


Figure 2: Cohort members with ASD by timing of diagnosis, in NEET (red) and not NEET (grey)

Hypothesis 2: Socioeconomic variables predict NEET status for CMs with ASD

The influence of the covariates is presented in table 2 and discussed in three instances: income, social skills, and carer variables.

Table 2: Odds ratio of NEET for cohort members with an ASD diagnosis

	OR	Std. error	p-value	95% CI lower	95% CI upper
OECD UK Equivalised income quintiles:	1.000	0.000			
<i>Lowest quintile</i>					
<i>Second quintile</i>	0.865	0.147	<0.3955	0.620	1.208
<i>Third quintile</i>	0.455*	0.083	<0.0005	0.318	0.651
<i>Fourth quintile</i>	0.230*	0.048	<0.0005	0.153	0.346
<i>Highest quintile</i>	0.103*	0.028	<0.0005	0.060	0.175
<i>SDQ Conduct Problems</i>	1.391*	0.042	<0.0005	1.311	1.477

<i>SDQ Total Difficulties</i>	1.119*	0.010	<0.0005	1.099	1.140
<i>SDQ Hyperactivity/Inattention</i>	1.258*	0.030	<0.0005	1.200	1.319
<i>SDQ Peer Problems</i>	1.255*	0.039	<0.0005	1.181	1.333
<i>SDQ Emotional Symptoms</i>	1.232*	0.031	<0.0005	1.173	1.294
<i>Carer with high score on Kessler 6</i>	2.779*	0.531	<0.0005	1.910	4.042
<i>Carers are not in work</i>	3.122*	0.475	<0.0005	2.317	4.206

1. Income

Firstly, living in poverty played a considerable role, as depicted by figure 3. CMs with ASD living in households in the median, second highest and highest income quintiles were respectively 54.5%, 77.0% and 89.7% less likely to be in NEET than their peers with ASD in the two lowest income brackets. Taking the three highest income quintiles as a base category, belonging to the two lowest UK income quintiles increased odds of NEET by a factor of 3.761 for CMs with ASD ($p < 0.0005$, 95% CI [2.923; 4.840]). However, further investigation revealed that those in two lowest income brackets were also 180% (p -value < 0.001 , 95% CI:[1.464;2.385]) times more likely to receive an ASD diagnosis.

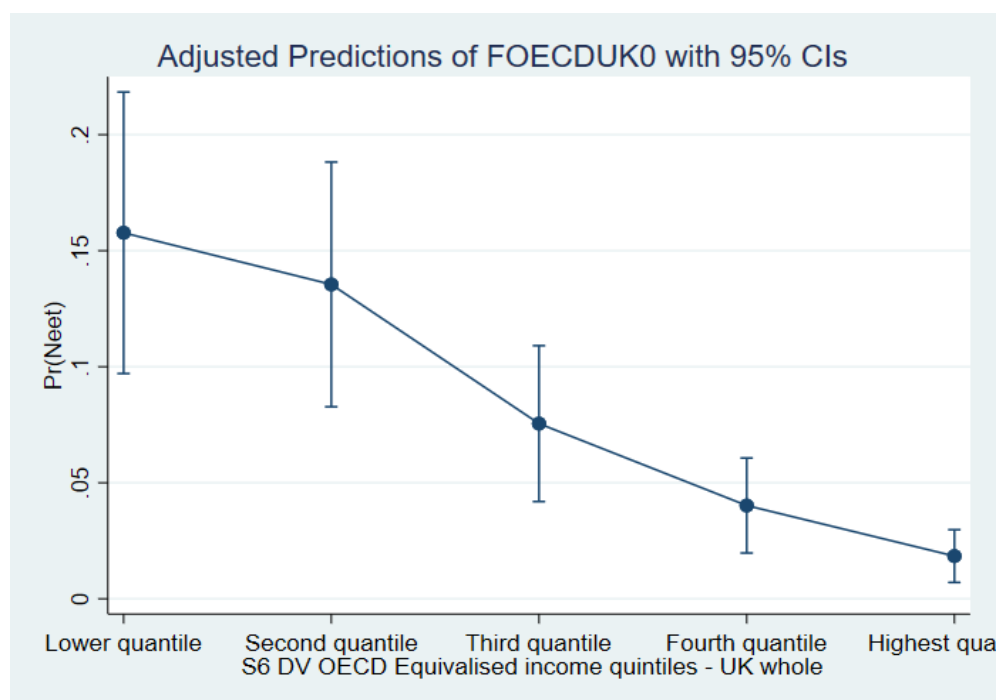


Figure 3: Predicted probability of NEET for ASD cohort members as a function of their household's OECD UK income quintile

2. Social skills as measured by the SDQ questionnaire

Secondly, all SDQ difficulties correlated with higher risks of NEET for ASD cohort members. Modelling NEET odds as a binary logistic regression of ASD diagnosis and SDQ total difficulties score alone revealed that ASD with ASD and a high SDQ total difficulties score had 4.030 ($p < 0.0005$, 95% CI: [3.045;5.332]) times higher odds of being NEET than other CMs with ASD. Most strikingly, as presented in Table 2 and taking all other SDQ subscales into account, an additional point on a CM with ASD's SDQ conduct score alone increases their risk of NEET by almost 40% (39.1%, 95% CI: [1.311;1.477]). Predicted probabilities were computed post-estimation and are presented below for CMs with and without ASD. In each case, the probability of NEET increases with the CMs difficulty score and is higher for those with ASD, despite overlaps in confidence intervals. Emotional Symptoms and Conduct Problems seem to highlight the greatest difference between those with and without ASD. For example, a CM with ASD and a score of 12 on both the Emotional Symptoms and Conduct Problems subscales would have a predicted probabilities of being in NEET ($Pr(NEET)$) to be respectively ≈ 0.35 and ≈ 0.61 , where as a CM with the same scores without ASD would have $Pr(NEET)$ of respectively ≈ 0.2 and ≈ 0.5 . The graph of NEET per conduct problems is notable for its sigmoid distribution, which shall be discussed later.

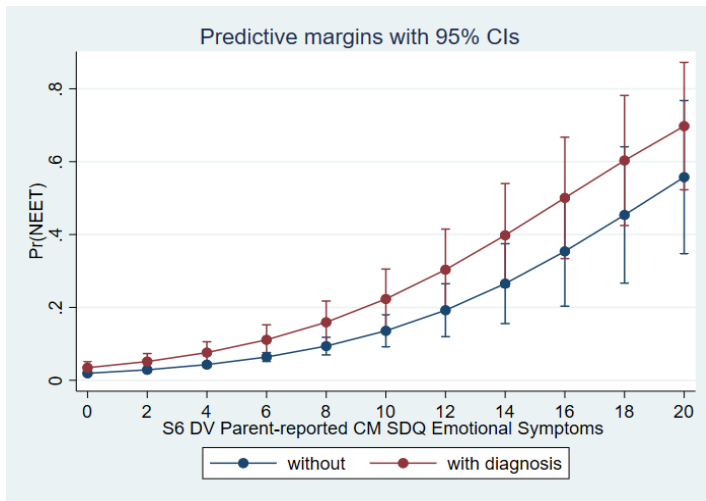


Figure 4: Predictive margins of NEET by SDQ Emotional Symptoms for cohort members with and without ASD diagnosis

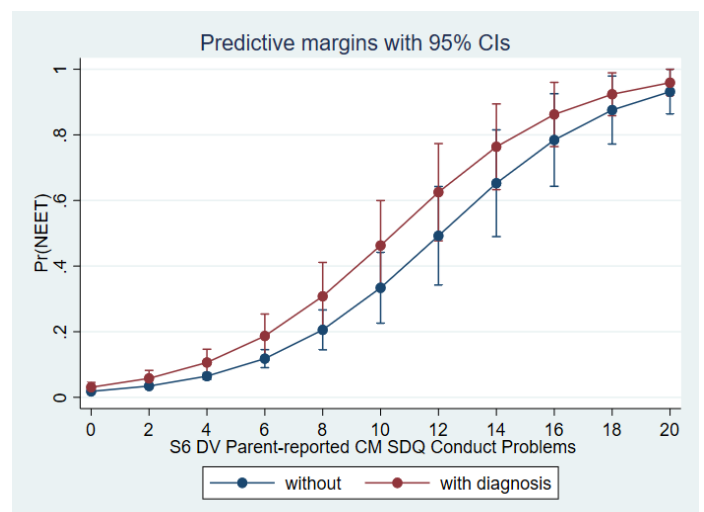


Figure 5: Predictive margins of NEET by SDQ Conduct Problems for cohort members with and without ASD diagnosis

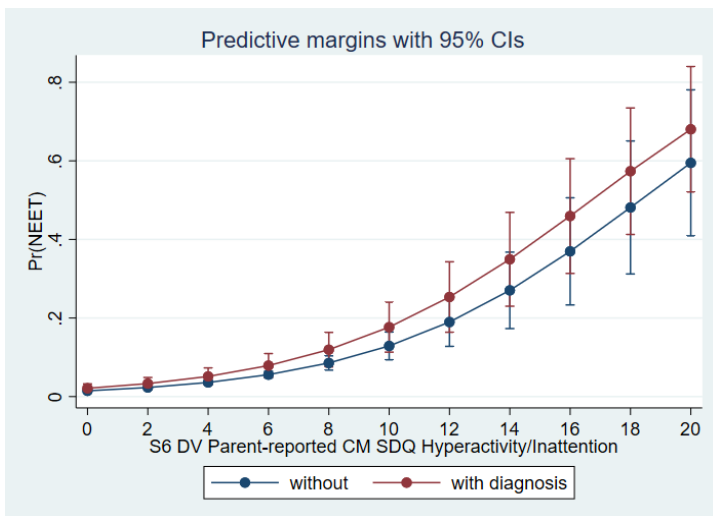


Figure 6: Predictive margins of NEET by SDQ Peer Problems for cohort members with and without ASD diagnosis

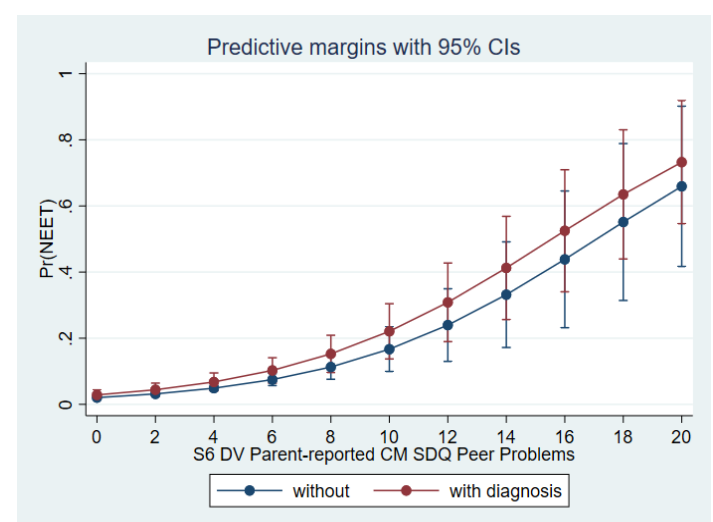


Figure 4: Predictive margins of NEET by SDQ Hyperactivity/Inattention for cohort members with and without ASD diagnosis

3. Carer variables and cognitive ability

ASD diagnosed cohort members with carers not in work were 312.3% (95% CI: [1.910; 4.206]) more likely to be in NEET. Furthermore, those whose carers scored in the top 5% of weighted Kessler 6 parental mental health scales in MCS6 had odds of being in NEET higher by a factor of 277.9% (95% CI: [1.910; 4.042]). As illustrated by Figure 8, the predicted probability of NEET increases with the carer’s Kessler 6 score. However, CMs with ASD register a probability twice as high than a CMs without ASD diagnosis for carers with identical score.

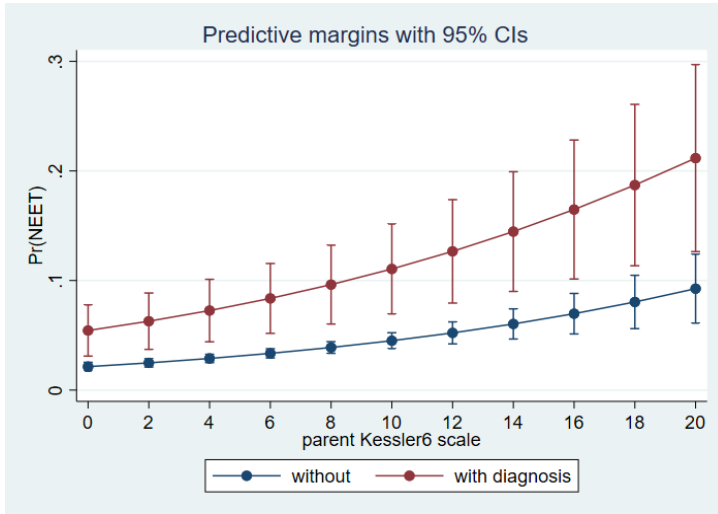


Figure 8: Predictive margins of NEET by parent Kessler 6 score (mcs6) for cohort members with and without ASD diagnosis

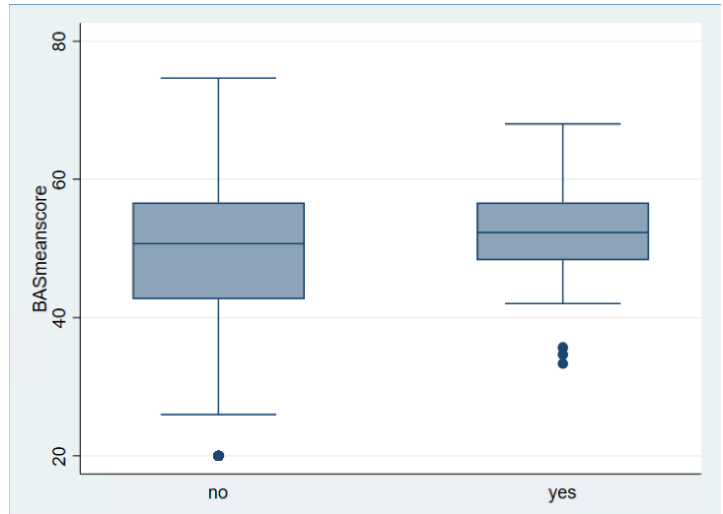


Figure 9: boxplot of mean BAS scores for ASD cohort members in NEET (yes) and not in NEET (no)

Importantly, though BAS II age 5 evaluations were found to influence the risk of neurotypical cohort members being in NEET, the score had no effect on NEET likelihood for children with ASD. This is illustrated by figure 9, as the mean for ASD cohort members in NEET is in fact higher than those ASD cohort members not in NEET.

Hypothesis 3: ASD diagnosis predicts projected life achievements for age 30

Projected life achievements at 30 yields strikingly different answers based on ASD diagnosis. As presented in Table 3, having an ASD diagnosis predicted 40% lower odds of having a partner (95% CI: [0.401;0.911]) and 50.7% lower odds of having children (95% CI: [0.300;0.809]), 51.7% lower odds of taking a worthwhile job (95% CI: [0.317;0.734]) or 511.8% higher odds of not expecting to have achievements listed in the covariates section when they reach at 30 years of age. Furthermore, as expected from higher NEET cases for ASD adolescents, the odds of ASD respondents reporting themselves as being likely to attend university were 56.5% lower compared to non-ASD respondents.

Table 3: ASD as a predictor of answers to aspirational questions from “Learning and The Future” of MCS7

	ASD status: diagnosed				
	OR	Std. error	p-value	95%CI lower	95%CI upper
Projected partner at 30	0.604*	0.126	<0.016	0.401	0.911

<i>Expectancy of children at 30</i>	0.493*	0.125	<0.005	0.300	0.809
<i>Projected worthwhile job at 30</i>	0.483*	0.103	<0.001	0.317	0.734
<i>Negative answers to all aspirational questions</i>	5.118*	2.419	<0.001	2.026	12.926
<i>Perceived likelihood of attending university</i>	0.435*	0.097	<0.0005	0.281	0.675

Including time of diagnosis sheds a light on the disparities in aspirations within the ASD cohort. As laid out in the subsequent tables, earlier diagnosis correlates with lower rates of positive answers to the prospect of social achievements (concerning children, having a partner, or holding any of the listed achievement) but higher rates of positive answers to the two employability questions (being in a worthwhile job and going to university) relative to those ASD adolescents with a later diagnosis. This confirms what was seen in the correlation between the timing of receiving ASD diagnosis and NEET status. Those without cognitive delay are at higher risk of late diagnosis (Hosozawa, M. *et al.*, 2020) which could relate to higher rates of NEET among late diagnosed ASD cohort members, and so lower professional aspirations.

Table 4: ASD and timing of diagnosis as a predictor for expecting to be in a worthwhile job at 30

	<i>OR</i>	<i>Std. error</i>	<i>p-value</i>	<i>95%CI lower</i>	<i>95%CI upper</i>
ASD status <i>with diagnosis</i>	.551*	.068	<0.000	.432	.703
ASD diagnosis timing <i>between 7 & 11</i>	.617*	.123	<0.016	.416	.914
<i>after 11</i>	.482*	.103	<0.001	.317	.734
<i>by age 5</i>	.606	.170	<0.076	.349	1.054

Table 5: ASD and timing of diagnosis as a predictor for expecting none of the listed aspirations from themselves at 30

	<i>OR</i>	<i>Std. error</i>	<i>p-value</i>	<i>95%CI lower</i>	<i>95%CI upper</i>
--	-----------	-------------------	----------------	--------------------	--------------------

ASD status	4.485*	1.3678	<0.0005	2.467	8.154
with diagnosis					
ASD diagnosis timing	3.722*	1.942	<0.012	1.338	10.353
between 7 & 11					
after 11	5.117*	2.419	<0.001	2.026	12.925
by age 5	7.676*	4.085	<0.0005	2.705	21.783

Table 6: ASD and timing of diagnosis as a predictor for expecting to have children at 30

	OR	Std. error	p-value	95%CI lower	95%CI upper
ASD status	.412*	.064	<0.0005	.302	.559
with diagnosis					
ASD diagnosis timing	.473*	.116	<0.002	.292	.766
between 7 & 11					
after 11	.492*	.124	<0.005	.300	.808
by age 5	.287*	.117	<0.002	.129	.638

Table 7: ASD and timing of diagnosis as a predictor for expecting to have a partner at 30

	OR	Std. error	p-value	95%CI lower	95%CI upper
ASD status	.461*	.058	<0.0005	.360	.592
with diagnosis					
ASD diagnosis timing	.409*	.086	<0.0005	.271	.619
between 7 & 11					
after 11	.604*	.126	<0.016	.401	.911

by age 5 .336* .103 <0.000 .184 .615

Table 8: ASD and timing of diagnosis as a predictor for perceived likelihood of attending university

	<i>OR</i>	<i>Std. error</i>	<i>p-value</i>	<i>95% CI lower</i>	<i>95% CI upper</i>
ASD status	.476*	.062	<0.0005	.370	.615
<i>with diagnosis</i>					
ASD diagnosis timing	.407*	.089	<0.0005	.265	.624
<i>between 7 & 11</i>					
<i>after 11</i>	.435*	.097	<0.000	.281	.675
<i>by age 5</i>	.917	.255	<0.756	.531	1.583

Discussion

1st Hypothesis

This study sought to draw a profile of NEET prospects for the 280 adolescents with ASD within the Millennium Cohort Study. ASD adolescents were found to be at least 3 times more likely to be in NEET than their neurotypical counterparts, corroborating the project’s first hypothesis. Higher rates of NEET status for CMs with ASD in the MCS is consistent with higher unemployment levels for adults with ASD in Sweden (Lallukka, 2020) and USA (Ohl, A. *et al.*, 2017).

2nd Hypothesis

The second hypothesis - that specific socioeconomic variables predict NEET status for ASD individuals - is supported by the influence of income, social skills, timing of diagnosis, parental variables over NEET status for ASD cohort members.

Late diagnosis seems to play a large role: a diagnosis by the age of five yields little significance while those diagnosed after 11 are five times more likely to be in NEET than those without. Moreover, in the context of ASD, NEET outcomes seem largely due to problems of socialisation, as illustrated by the prevalence of poor behavioural scores rather than cognitive delay for adolescents with ASD in NEET. As such, those diagnosed late with poor social skills are most at risk of being in NEET without a considerable importance of their cognitive ability.

Two notes can be added to these results. First, the predicted probabilities of NEET as a function of cohort member’s conduct problems’ score seems to follow a sigmoid distribution. Thus, there appears to be a threshold - around a score of 11 - beyond which cohort members’ conduct problems overwhelm their environment’s ability to prepare them for education, training or employment. Second, the insignificance of cognitive ability could also be explained by later diagnosis for those without cognitive delays, thus benefiting from less help with social skills early on. These results encourage significance of early and timely interventions.

In tandem, within the MCS cohort that was studied, lower incomes present a greater weight for ASD adolescents regarding the likelihood of NEET status. Three initial explanations can be outlined. Firstly, as elucidated by Hosozawa *et al* (2020), lower income groups within the MCS are skewed towards later diagnosis despite previous contradictory studies (Brett, D., Warnell, F., McConachie, H. *et al.*, 2016) on ASD in the UK. Thus, as poorer households would have received later diagnosis, financial deprivation is coupled by belated interventions. Second and more strikingly, further analysis of MCS data reveals that any ASD diagnosis is also predicted by lower incomes. This could be due to an initial deprivation of needs exacerbating anxiety or isolation, and hence of social difficulties. Equally, this result could be related to earlier biological factors, such as poor nutrition and birth weight affecting later socioemotional development (Hosozawa, M., *et al.*, 2021). Thirdly, although US studies found no extra out-of-pocket costs for parents of children with ASD (Tara A. *et al.*, 2014), a last explanation for the prevalence of NEET among ASD adolescents in lower income quintiles could be the inability of parents to provide extra health care services, office visits or specialised education schemes associated with the upbringing of a child with ASD (Tara A. *et al.*, 2014).

Finally, having parents out of work and with poor mental health also predicted NEET. Caregiver strain is higher for parents of children with ASD (Bradshaw, J. *et al.*, 2021), so it could be that poor parental mental health is linked to those CMs with ASD and high SDQ scores already at risk of being NEET. Poor parental mental health could also affect the CM's support through specialised care systems, increasing his/her risk of being NEET. Whether or not parental mental health is a cause or a consequence of CMs with higher risk of NEET status, it appears to be a red flag at age 14 for within the MCS.

3rd Hypothesis

The final hypothesis, that ASD diagnosis predicts an answer to projected life achievements, was equally corroborated, with ASD CMs being 5 times more likely to say they did not see themselves with any of the listed achievements.

The responses to life achievement at 30 highlight the progress that can still be made in the social integration of ASD individuals. Higher rates of cohort members with later diagnoses see themselves with children or partners at 30 than those who were diagnosed early, supporting previous findings that those diagnosed later seem more socially adept (Hosozawa, M. *et al.*, 2020). Notwithstanding, later diagnosed cohort members also had lower professional expectations, as fewer saw themselves in a worthwhile job or at university. In summary, later diagnosed individuals seem to have had greater social confidence but diminished professional aspirations compared to earlier diagnosed cohort members. The case of adolescents with ASD in NEET could suggest a case of nurture over nature.

Policy implications

These results corroborate the success of early interventions in not only improving social skills (Green, J. *et al.* 2010; Pickles, A. *et al.* 2016), cognitive ability (Turner, L. M. *et al.*, 2006) and lowering risk of depression (Hosozawa, M. *et al.*, 2021), but also consequently reducing the likelihood of NEET status in adolescence. Further, the unimportance of language spoken at home for the UK cohort with ASD contrasts with a similar study for non-English speaking households in the US (Lin, S., Yu, S., 2014, p159). This could suggest a more navigable health system under universal care than under a coordination of private institutions for foreign-language households.

It should be noted that social skills rather than cognitive delay predicted NEET. To reduce the gap in NEET rates between ASD and neurotypical adolescents, early diagnosis and intervention that target social development, such as JASPER (Lawton, K. Kasari, C., 2012; Goods, K.S., *et al.* 2013; Kasari, C., *et al.*, 2010), LEAP (Strain, P.S., Bovey E.H., 2011), TEACCH (Virues-Ortega, J., Julio, F. M., Pastor-Barriuso, R., 2013) could require further expansion. Not only could this avoid inactivity in youth, but educational attainment has been found to equally predict employment for adults with autism later in life (Ohl, A. *et al.*, 2017).

This said, investment in early intervention and diagnosis should not be at the expense of later care. Patterns of behaviour that develop in adolescence such as sleep disorders have been shown to hold considerable influence on later employment for individuals with ASD and average cognitive ability (Baker, E. K., Richdale, A. L. and Hazi, A., 2019). Teenagers with ASD could therefore be equally in need of attention. A case study in China (Liu,

F., Liu, S., Chai, J., 2020) has found institutions capable of teaching children with ASD but an absence of integration for the same adults. As echoed by a study of adults with ASD and no cognitive impairment in Germany, standard education alone is not necessarily sufficient (Riedel A, Schröck C, Ebert D, *et al.* 2016) and there are substantial benefits to social interventions in later life (Howlin, P. *et al.* 2013). Schemes such as PEERS offer similar substantial evidence of the effectiveness of intervention for adolescents and young adults in improving social skills (Lemmi, V. *et al.*, p64). In brief, later diagnosis is not deterministic and adolescents with ASD's social skills can improve, simultaneously reducing their probability of NEET status.

Finally, as parental mental health was also found to be a predictor of NEET, parental schemes could also benefit those growing up with ASD. Parental training has been found to reduce children with ASD's disruptive behaviour as well as parent stress (Ladarola, S. *et al.*, 2018), both of which link positively to NEET. This report thus argues for the need of further attention to support parents.

Strength and Limitations

This study utilised data from the Millennium Cohort study, hence benefitting from a longitudinal perspective. Nevertheless, statistical power was sacrificed by opting for a complete case analysis with no imputation. Further, although the 280 ASD individuals studied in our analysis is a similar size to other cohort studies, it is relatively small compared to the 7,636 cohort members without ASD. The latter offers greater power in generating its conclusion.

Moreover, this survey relied on parental reports of ASD diagnosis which could change throughout the sweep without updating the interviewer and did not report on diagnosis past 14 years old. This was partly addressed by Hosozawa *et al.* (2020): parent reported ASD diagnosis has demonstrated good reliability (Daniels & Mandell, 2014; Kogan *et al.*, 2009; Miodovnik *et al.*, 2015; Sheldrick *et al.*, 2017), and revocation of ASD diagnosis has not been shown to have a strong influence. It could also be argued that diagnosis past 14 suggests strong aptitudes to coping with a neurotypical education and context, therefore having a minor effect on NEET prospects.

Finally, a considerable handicap is the possible missing input from individuals with ASD who had severe cognitive delays or motor disability, unable to complete the surveys. This study found 18.21% of its cohort with ASD to suffer from cognitive delay. This is within the range of values brought up in the introduction (13% to 80%), so the number of missing cohort members with ASD could be negligible, although caution should still be taken in approaching this study's results.

Conclusion

By investigating the prevalence and determinants of NEET status for adolescents with ASD, this study has measured the impact of income, social skills and early diagnosis in their early life trajectories. It has concluded that, while cognitive impairment plays no role in ensuring adolescents with ASD's preparation to the workforce, late diagnosis, low income and poor behaviour puts them at high risk of being in NEET. As a consequence, it is advisable that the successes of early diagnosis and intervention be expanded and enhanced by effective later interventions.

Further research should be conducted into how adults in the MCS with ASD evolve from their early NEET status. Additionally, rich insights could be gained by complementing this research with studies outside the UK to evaluate the influence of differing health and education systems.

References

- American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.).
- Baio, J., Wiggins, L., Christensen, D., *et al.* (2014). 'Prevalence of autism spectrum disorder among children aged 8 years: Autism and Developmental Disabilities Monitoring Network', *Morbidity and Mortality Weekly Report Surveillance Summaries*, Volume 67(6), pp 1–23. Available at: [http://dx.doi.org/10.15585/mmwr.ss6706a1external icon](http://dx.doi.org/10.15585/mmwr.ss6706a1external%20icon).
- Baker, E., Richdale, A. and Hazi, A. (2019). 'Employment status is related to sleep problems in adults with autism spectrum disorder and no comorbid intellectual impairment', *Autism*, Volume 23(2), pp, 531–536. doi: [10.1177/1362361317745857](https://doi.org/10.1177/1362361317745857).
- Brett, D., Warnell, F., McConachie, H. *et al.* (2016). 'Factors Affecting Age at ASD Diagnosis in UK: No Evidence that Diagnosis Age has Decreased Between 2004 and 2014', *J Autism Dev Disord*, Volume 46, pp. 1974–1984.
- Bradshaw, J., Gillespie, S., McCracken, C., *et al.* (2021). 'Predictors of Caregiver Strain for Parents of Children with Autism Spectrum Disorder', *J Autism Dev Disord*, Volume 51. pp 3039–3049. Available at: <https://doi.org/10.1007/s10803-020-04625-x>
- Buescher, AVS, Cidav, Z, Knapp, M, Mandell, D. (2014). 'Costs of Autism Spectrum Disorders in the United Kingdom and the United States'. *JAMA Pediatrics*. 2014;168(8):721–728. Available at: doi:10.1001/jamapediatrics.2014.210
- Clark, M., Vinen, Z., Barbaro, J. *et al.* (2018). 'School Age Outcomes of Children Diagnosed Early and Later with Autism Spectrum Disorder', *J Autism Dev Disord*, Volume 48. pp 92–102.
- Fitzsimons, E., Haselden, L., Smith, K., *et al.* (2020). *Millennium Cohort Study Age 17 Sweep (MCS7): User Guide*. London: UCL Centre for Longitudinal Studies.
- Green, J., Charman, T., McConachie, H. *et al.* (2010). 'Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial.', *The Lancet*, Volume 375(9732), pp. 2152-2160.
- Goods, K.S., Ishijima, E., Chang, Y.C., Kasari, C. (2013). 'Preschool based JASPER intervention in minimally verbal children with autism: Pilot RCT', *Journal of Autism and Developmental Disorders*, Volume 43, pp. 1050-1056.94
- Hansen, K. (2014). *Millennium Cohort Study: A guide to the datasets* (7th ed.). Centre for Longitudinal Studies, UCL Institute of Education, University College London.
- Hosozawa M, Cable N, Kelly Y, *et al* (2021). 'Gestational age on trajectories of social competence difficulties into adolescence', *Archives of Disease in Childhood*. doi: 10.1136/archdischild-2020-321317
- Hosozawa, M., Mandy, W., Cable, N. *et al.* (2021). 'The Role of Decision-Making in Psychological Wellbeing and Risky Behaviours in Autistic Adolescents Without ADHD: Longitudinal Evidence from the UK Millennium Cohort Study', *J Autism Dev Disord*, 51, pp.3212–3223. Available at: <https://doi.org/10.1007/s10803-020-04783-y>

- Hosozawa, M., Sacker, A. & Cable, N. (2021) 'Timing of diagnosis, depression and self-harm in adolescents with autism spectrum disorder', *Autism*, 25(1), pp. 70–78. doi: [10.1177/1362361320945540](https://doi.org/10.1177/1362361320945540).
- Hosozawa, M., Sacker, A., Mandy, W. *et al.* (2020) 'Determinants of an autism spectrum disorder diagnosis in childhood and adolescence: Evidence from the UK Millennium Cohort Study', *Autism*, 24(6), pp. 1557–1565. doi: [10.1177/1362361320913671](https://doi.org/10.1177/1362361320913671).
- Howlin, P. Moss, P. Savage, S. and Rutter, M. (2013). 'Social Outcomes in Mid- to Later Adulthood Among Individuals Diagnosed with Autism and Average Nonverbal IQ as Children', *Journal of the American Academy of Child & Adolescent Psychiatry*, Volume 52(6), pp. 572-581. Available at: <https://doi.org/10.1016/j.jaac.2013.02.017>.
- Howlin, P. & Magiati, I (2017). *Current Opinion in Psychiatry*, Volume 30, Number 2, pp. 69-76(8)
- Iadarola, S., Levato, L., Harrison, B. *et al.* (2018). 'Teaching Parents Behavioral Strategies for Autism Spectrum Disorder (ASD): Effects on Stress, Strain, and Competence.', *J Autism Dev Disord*, 48, pp.1031–1040. Available at: <https://doi.org/10.1007/s10803-017-3339-2>
- Iemmi, V., Knapp, M., & Ragan, I. (2017). *Autism Dividend*. Michael Smith Foundation for Health Research (MSFHR).
- Kasari, C., Gulsrud, A.C., Wong, C. *et al.* (2010). 'Randomized controlled caregiver mediated joint engagement intervention for toddlers with autism', *Journal of Autism and Developmental Disorders*, 40, pp. 1045-105.
- Kelly, Y. J., Sacker, A., Gray, R., Kelly, J., Wolke, D., Head, J., & Quigley, M. A. (2012). 'Light drinking during pregnancy: still no increased risk for socioemotional difficulties or cognitive deficits at 5 years of age?', *Journal of epidemiology and community health*, 66(1). pp 41–48.
- Kessler, R., Barker, P., Colpe, L., *et al.* (2003). 'Screening for Serious Mental Illness in the General Population', *Arch Gen Psychiatry*, 60(2). pp.184–189. doi:10.1001/archpsyc.60.2.184.
- Licari, M., Alvares, G., Varcin, K., *et al.* (2020). 'Prevalence of Motor Difficulties in Autism Spectrum Disorder: Analysis of a Population-Based Cohort', *Autism Research*, 13, pp.298-306. Available at: <https://doi.org/10.1002/aur.2230>
- Lord, C., Elsabbagh, M., Baird, G. and Veenstra-Vanderweele, J. (2018). 'Autism spectrum disorder', *The Lancet*, Volume 392 (10146). pp.508-520. Available at: [https://doi.org/10.1016/S0140-6736\(18\)31129-2](https://doi.org/10.1016/S0140-6736(18)31129-2)
- Lallukka, T., Mittendorfer-Rutz, E., Ervasti, J. *et al.* (2020). 'Unemployment Trajectories and the Early Risk of Disability Pension among Young People with and without Autism Spectrum Disorder: A Nationwide Study in Sweden', *International Journal of Environmental Research and Public Health*, 17(7), 2486. Available at: <https://doi.org/10.3390/ijerph17072486>
- Lavelle, T., Weinstein, C., Newhouse, J., *et al.* (2014). 'Economic Burden of Childhood Autism Spectrum Disorders', *Pediatrics*, 133(3), pp.520-529. Available at: <https://doi.org/10.1542/peds.2013-0763>

- Lawton, K. and Kasari, C. (2012). 'Teacher-implemented joint attention intervention: Pilot randomized controlled study for preschoolers with autism.', *Journal of Consulting and Clinical Psychology*, 80, pp.687-693.
- Lin, S. and Yu, S. (2014). 'Disparities in healthcare access and utilization among children with autism spectrum disorder from immigrant non-english primary language households in the united states', *International Journal of MCH and AIDS*, ISSN: 2161-8674, Volume 3(2), pp. 159-167. Available at: <https://doi.org/10.21106/ijma.48>
- Liu, F., Liu, S. and Chai, J. (2020). 'Problems in treatment and training of autistic children growing up in China: A follow-up case report.', *Pediatrics Invest.* Volume 4, pp. 138– 140. Available at: <https://doi.org/10.1002/ped4.12200>
- Ohl, A., Grice Sheff, M., Small, S. *et al.* (2017). 'Predictors of Employment Status Among Adults with Autism Spectrum Disorder', *Work*, Volume (56), no.2, pp. 345 – 355. doi: 10.3233/WOR-172492
- Pickles, A., Le Couteur, A., Leadbitter, K. *et al.* (2016). 'Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial', *The Lancet*, 388, 2501-25. doi: 10.1016/S0140-6736(10)60587-9
- Midouhas, E., Yogaratnam, A., Flouri, E. and Charman, T. (2013). 'Psychopathology Trajectories of Children with Autism Spectrum Disorder: The Role of Family Poverty and Parenting', *Journal of the American Academy of Child & Adolescent Psychiatry*, Volume 52(10), pp. 1057-1065.
- Riedel, A. Schröck, C., Ebert, D., *et al.* (2016). 'Well Educated Unemployed--On Education, Employment and Comorbidities in Adults with High-Functioning Autism Spectrum Disorders in Germany.' *Psychiatrische Praxis*, Volume 431. pp. 38-44. doi: 10.1055/s-0034-1387494.
- Russell, G., Rodgers, L., Ukoumunne, O., *et al.* (2014). 'Prevalence of Parent-Reported ASD and ADHD in the UK: Findings from the Millennium Cohort Study', *J Autism Dev Disord*, 44. pp.31–40.
- Sprent P. (2011). 'Fisher Exact Test', *International Encyclopedia of Statistical Science*, Springer, Available at: https://doi.org/10.1007/978-3-642-04898-2_253
- StataCorp. (2019). *Stata Statistical Software: Release 16*. College Station, TX: StataCorp LLC.
- StataCorp. (2021). *Stata Statistical Software: Release 17*. College Station, TX: StataCorp LLC.
- Strain, P.S. and Bovey, E.H. (2011). 'Randomized, controlled trial of the LEAP model of early intervention for young children with autism spectrum disorders.' *Topics in Early Childhood Special Education*, Volume 31. pp. 133-154.
- Turner, L., Stone, W., Pozdol, S. *et al.* (2006). 'Follow-up of children with autism spectrum disorders from age 2 to age 9', *Autism*, Volume 10(3), pp. 243–265. doi: [10.1177/1362361306063296](https://doi.org/10.1177/1362361306063296).
- Virues-Ortega, J., Julio, F. M. and Pastor-Barriuso, R. (2013). 'The TEACCH program for children and adults with autism: A meta-analysis of intervention studies.' *Clinical Psychology Review*, Volume 33, pp. 940-953.